CHILD AND ADOLESCENT PSYCHIATRY SURVEILLANCE SYSTEM (CAPSS)

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Incidence of Avoidant/Restrictive Food Intake Disorder (ARFID) in children and young people presenting to secondary care in the UK and Ireland.

ARFID was a new diagnosis in DSM-5 (Diagnostic and Statistical Manual of Mental Disorders-5, 2013) and in ICD-11 (WHO International Classification of Diseases-11, to come into effect from January 2022), replacing Feeding Disorder of Infancy and Early Childhood and encompassing several terms previously used to describe restrictive eating patterns presenting clinically but not meeting criteria for an eating disorder. There are limited research data on ARFID and the percentage of people thought to have a diagnosis of ARFID differs by country and by type of study. A surveillance study undertaken in Canada (CPSP) identified 180 new cases of ARFID over 24 months, average age 13.0 years, 61% females and 39% males, with the majority of children and adolescents in treatment.

Introduction to the study

The study aims to collect data on Avoidant/Restrictive Food Intake Disorder (ARFID), a mental and behavioural disorder diagnosis introduced in 2013. ARFID is an umbrella term used to describe restrictive eating patterns which result in significant health problems, including weight loss, poor growth, nutritional deficits or poor emotional wellbeing. Unlike in anorexia nervosa, restrictive eating in ARFID is not associated with concerns about body image, weight or shape.
By using questionnaires sent to paediatricians through the British Paediatric Surveillance Unit (BPSU) and child and adolescent psychiatrists through the Child and Adolescent Psychiatric Surveillance system (CAPSS), this study aims to establish incidence rates of ARFID presenting to secondary health care, referral pathways, patterns of presentation, and clinical features in the United Kingdom and Ireland. This will allow us to compare rates, presentation and management of ARFID with other countries, as well as generating new priority research questions that could in turn inform decision making to better match patient need with sufficient funding allocations.

How long will it go on for?

CAPSS surveillance will be undertaken for 13 months, commencing in March, 2021**.** There will be a 1-year follow-up questionnaire for each case reported.

Who should be contacted if I have any questions about this study?

Please contact CAPSS: CAPSS@rcpsych.ac.uk

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https://www.rcpsych.ac.uk/improving-care/ccqi/research-and-evaluation/current-research/capss

CASE DEFINITION

Any child or adolescent aged 5 to 17 years with persistent restriction of quantity and/or range of food intake, associated with one or both of the following:

- Nutritional deficiency that requires additional clinical investigation or treatment (e.g. anaemia, micronutrient deficiency, weight loss or poor growth, reliance on nutritional supplementation) that is not fully accounted for by poverty or neglect, cultural practice or an existing medical condition or another mental disorder*
- Interference with day-to-day functioning due to eating behaviour (e.g. unable to eat at school or with peers, needs to take preferred foods when out of home, extreme and frequent distress about eating).

Not explained by ANY of the following:

- Lack of available food (e.g. from poverty, famine or neglect)
- Culturally sanctioned practice (e.g. endorsed religious and cultural practice)
- Other known diagnosis
    - e.g. Allergy to specific food group (e.g. dairy)
    - Gastrointestinal disorder
    - Constipation
    - Swallowing difficulties
    - Other eating disorder e.g. anorexia nervosa, bulimia nervosa
    - Other medical or psychiatric disorder that fully explains food restriction (not requiring additional clinical attention) e.g. depression, anxiety, OCD, malignancy, diabetes mellitus, inflammatory bowel disease, thyroid disease

*If eating disturbance occurs in the context of another condition/disorder, then in order to meet case definition for ARFID, the severity of eating disturbance should exceed that routinely associated with the particular condition/disorder - and warrant additional clinical attention.

Duration

CAPSS surveillance will be undertaken for 13 months, commencing in March, 2021. There will be a 1-year follow-up questionnaire for each case reported.

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Ethics approval

The study has been approved by West Midlands - Black Country Research Ethics Committee - 20/WM/0256; HRA Confidentiality Advisory Group - 20/CAG/0120; Public Benefit and Privacy Panel for Health and Social Care (HSC-PBPP) - 2021-0113; Northern Ireland Privacy Advisory Committee requirements were met.

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References: https://www.cpsp.cps.ca/uploads/publications/CPSP-2017-Results_1.pdf